DOCUMENT RESUME

ED 385 085 EC 304 118

AUTHOR Pitts, Raymond J., Jr.; Marchitell, Carolyn K.
TITLE Rays of Hope: The Special Child and the Family.
PUB DATE 95
NOTE 67p.; Photographs may not reproduce well.
AVAILABLE FROM Communication Arts, 3 Dayleview Rd., Berwyn, PA 19312-1293.
PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Adolescents; Adults; *Child Rearing; Children; *Coping; Decision Making; Disability Identification; *Emotional Adjustment; Family Problems; *Family Relationship; Family School Relationship; Infants; Long Range Planning; *Mental Retardation; *Parent Attitudes

ABSTRACT

This book illustrates techniques that families have found effective in coping with a family member who has mental retardation. It provides quotations and comments from a number of parents as well as anecdotal accounts and photographs, grouped into four sections. The first section is on the recognition process and recounts how parents have coped with the emotional trauma and imbalance as their feelings change from joy to sorrow and uncertainty when finding out and acknowledging that their child has mental retardation. The second section is on the dynamic process of dealing with fears, fantasies, and facts associated with the effects of the disability on the family dynamics. The third section stresses the working process which is using existing support systems and the exercising of rights when dealing with schools, programs, and placement decisions. The final section is on the future process--ways to prepare and position the family member with mental retardation for a lifetime. (DB)

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Rays of Hope

The Special Child and the Family

Raymond J. Pitts, Jr., Ph.D.
and Carolyn K. Marchitell, Ph.D.

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Rays of Hope

The Special Child and the Family

Raymond J. Pitts, Jr., Ph.D.
and Carolyn K. Marchitell, Ph.D.

Also:

Pitts, R. J., Jr., and Marchitell, C. K.:

Project Return: A Parent's Guidebook [1993]

Pitts, R. J., Jr.:

Success Factors in Group Home Programs for the Severely and Profoundly Retarded [1992]

Marchitell, C. K.:

Effect of Institutional Change on Perception of Control [1993]

"Learning to Lead" [1991]

"Evaluating the Performance of the Performance Evaluation" [1987]

"To Be or Not To Be Hunterized" [1986]
with Alice A. Campbell, M. A.

"Culture, Commitment, and the Computer" [1984]

Misunderstood Monster: Research Paper in the Classroom [1982]

Communication Arts
3 Dayleview Road
Berwyn, PA 19312-1293

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Our families are two of the thousands who have entered the special world of mental retardation.

Mary Dana Rentfrow, Carolyn's mother, is 82 years old, but she still coordinates the care of her 44-year-old profoundly retarded son. In 1950, she began to pioneer the territory which my own family has travelled, 28 years later. She let me read "Mike's Story," and she helped us develop a guidebook for parents. Mary insisted that we make this clear: "Parents bear the responsibility to keep track of all aspects of their handicapped child's life. That is as it should be, of course." She has never shirked in that responsibility. What she has shared privately can help many more people. Her decision to "go public" was the catalyst for this volume.

Conversations with many people about the trials and triumphs of their special families have helped us to make critical choices and to persevere in our work. To all of those sources, we are grateful.

In decisions about this volume, we especially thank

- *my father, Raymond J. Pitts, Ph. D.;*
- *Alice A. Campbell, M.A.;*
- *Mary D. Rentfrow, M.A.;*
- *and Kathleen S. Francis.*

Once, a friend spoke eloquently in response to heartfelt thanks for information vital to a handicapped child's future. The words were simple: "Pass it on."

***Rays of Hope** tells the journey of one special family, through a father's eyes. I hope it will help someone who follows, by "passing it on."*

Raymond J. Pitts, Jr.
July 1994

This book is about coping with the extraordinary adjustments and demands when families include a mentally retarded child. These families have special needs during four distinct phases of their growth together:

The recognition process:
Coping with emotional trauma and imbalance when families acknowledge that their new child has been born with mental retardation.

The dynamics process:
Understanding the effects on the family unit.

The working process:
Using existing support systems and exercising rights.

The future process:
Preparing and positioning the handicapped family member for lifetime.

The birth of a mentally handicapped child throws a family into crisis.

As in most crisis situations, denial, acknowledgement, acceptance, and coping with the realities of the child's limitations take on many forms. These, in turn, affect many facets of the life most touched by the special child: The Life of the Family.

Round-the-clock care, resource location, and strategic planning suddenly become lifetime priorities to ensure welfare, development, and integration into society for the handicapped family member.

Ultimately, the family unit is the one constant component in the care of the special child.

These are my reflections about the special child in our family.

Rays of Hope:
The Special Child and the Family

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A Child Is Born:

Joy,

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the Recognition Process

Joy

"It's A Boy!" That exuberant phrase was coined on the pins, balloons, and cards that my parents received from well-wishers after Raymond III was born. My parents and I were overwhelmed with joy to have Ray become part of our family in 1977.

My father was especially thrilled with the gender of his second child. Now my dad had a child who could carry on the family name of Pitts. However, I was delighted for different reasons. I was attaining another role in our family, namely "Big Sister." And I was getting a constant companion.

-- Rachel Pitts Corrigan, 1992

Rachel, our oldest child, could not have known how prophetic her image of "constant companion" was, nor how childlike her "little brother" would always be. She wrote those words many years later for a paper for her college psychology class. In the joyful tone of the excerpt, there isn't even a hint of the tribulations to come with the birth of a profoundly retarded brother. We *all* had to sort out the difference between fact and fantasy when Raymond was born.

Looking back, I can remember vividly the feeling of exhaustion after witnessing Raymond's birth. In a state of peaceful resolve, I went to pick up Rachel. Janice and I had left her with a neighbor as we rushed off to the hospital earlier that morning. She had been anxiously awaiting news of the birth.

> ***R**achel's first question was, "What color is he?"*

This was a logical question, coming from an eight year-old in a family with a mixed marriage. But I was filled with the excitement of announcing the birth of a son, so her question caught me off guard.

I wanted to keep the momentum of the excitement, so I responded:

> ***"H**e's exactly like you."*

That answer seemed to settle the issue for both of us, at least temporarily.

My mood was euphoric. When I called my father to announce Raymond III, I felt a wild satisfaction, sharing romantically in the feelings of my ancestors, knowing that a son had been born to carry the Pitts name into the next century. There was both relief and pride in knowing that we had brought another child safely into the family. My phone calls to friends and relatives relayed the news that both mother and son were fine. Everyone sent congratulations, wishing us well as we prepared for their homecoming.

It didn't occur to me that in the coming months, this uncompromised feeling of self-worth could be shattered, as I slowly became aware of the significance of my son's retardation.

I wasn't aware of my open vulnerability.

And I would never be that innocent again.

Sorrow

For me, recognition of our son's disability did not come in one dramatic moment. It was a slow process.

I remember being awakened suddenly by the nurse. She was saying that I should hurry if I wanted to witness the birth. Everything seemed rushed, but normal.

Somewhere in the middle--of what I heard, what I wanted to hear, and what actually was said--lay the truth.

Close friends of the family told us years later that they watched in fear as we tried to understand what was obvious to them from the beginning. And when we now look at early snapshots, the truth is apparent.

After grappling with private acceptance, I had to face public acknowledgement that my son was retarded. For several months, I was only able to say something was wrong with Raymond's sight.

Why did I have such trouble recognizing the truth? Because I was trying to reason it away.

There wasn't any history of retardation in our families. We knew such things could happen, but we didn't think it would strike us.

And when Raymond was born, the doctors had clearly stated that he was "normal." Even though there had been an atmosphere of emergency during the delivery, they hadn't once mentioned any problems.

My wife, Janice, and I had based our goals and dreams on a "normal" family life, with "normal" children.

For a long time, we were unaware of the extent of our son's malfunction, so discussions about his development were muddled and premature. But three months after Ray's birth, while we were vacationing on the island of Martha's Vineyard, a friend's honest observation made our sorrow painfully clear. John Patterson, Sr., was holding Raymond in his arms for a group picture.

> *"There's something wrong with this baby."*

His remark, offered with simple love and kindness, seemed to escape the attention of the other people vacationing with us. But later, Janice and I discussed what John had said. Privately, we could admit to each other the gigantic problem we both suspected. We simply hadn't been ready for conscious acknowledgement.

Without openness, we weren't able to get all the information we needed--separately, and as a family. Back then, we were easily confused by what sounded like mixed messages. People wanted to help us come to grips with reality, yet they wanted to be sensitive to our feelings. When we finally understood the seriousness of Raymond's retardation, we had to decide whether it was best for him to remain at home, living with the family or live in an institution. In either case, there would be enormous changes to our family.

Uncertainty

The move from fantasy to reality began when a case worker came to evaluate our situation and make recommendations. My mother came all the way from California to be with us for the discussion, and I could sense the seriousness and concern in her posture. We thought the statement would be emotional, but it wasn't. The assessment was simple:

> "R*aymond will need special training."*

At the time, we couldn't imagine what those words really meant, or what they might involve.

Throughout our adjustments to Raymond's slow development, information and advice came from several sources. We have come to think of these sources in three ways:

Our *inner circle*. For the most part, this circle consists of our parents and the relatives who had already been exposed to the world of special education.

Our *family of choice*. These intimate friends are, in their way, even closer to the family than some relatives. Usually, the title of "aunt" or "uncle" precedes their names, as a stamp of trust and love. Some people came into this circle through sharing the wounds and victories of their own struggles with retardation in their families. Some of them shared those struggles here, as well.

The *professionals*. These are the people in the field. They understand the situation from a different, factual perspective. School board representatives, special resource teachers, physical therapists, counselors, principals, case workers--they participate daily in the educational process for handicapped individuals.

When Raymond was three years old, Janice and I visited a highly recommended residential center. During our tour of the facility, we saw a child like Ray. He was confined in a cage-like apparatus which resembled a large baby crib, enclosed at the top. We were not prepared for life at this level. The revulsion of this experience--combined with the institution's fee of $30,000 a year--forced us to look for an alternative. We decided to keep Raymond living within the family unit and we moved forward with a positive outlook. I often wonder how different his life might be today if we had placed him in institutional care.

Raymond was assigned to an infant program at the Centers for the Handicapped, where we took him until he was five years old. There, we met other families who were learning to cope with their disappointment, and trying to get help for their children with mental disabilities. There, we also were introduced to the mandatory, bi-annual progress assessment sessions, at which parents and teachers agree upon goals and components of individualized programs. We reviewed reports about Raymond, and with the stroke of a pen, our signatures launched us onto the road we travel today.

I tried to keep an open mind. I joined other fathers as remote observers, while Janice and other mothers interacted with teachers and administrators. For a time, my response to this new world for Raymond was distant and theoretical. I thought I was comfortable with the routine of communications--until Raymond had an accident. A report said that our son should be carefully observed, because he had suffered a head bruise when he fell from the diaper-changing table. Suddenly, my response was urgent and particular.

I became more involved, visited more often, and learned the importance of parent advocacy. I felt encouraged in my involvement, as I began to experience a bonding with my son, and with the people who helped me through the realization that Raymond would not be "normal" during his lifetime. My concern for his safety and comfort remain steadfast to this day.

God doesn't burden you with a load you can't bear. Things happen for a reason.

The birth of our special child had thrown our light-hearted family dream into the dark mourning of cruel reality.

Those first few years were a struggle for ***recognition***--trying to understand our individual, shattered expectations.

I tried to hear what my own parents and sisters were saying about assuming charge of Ray's future.

My wife worked to remain supportive in her own dependable way.

Because she didn't have anyone to talk to, our daughter Rachel suffered in silence.

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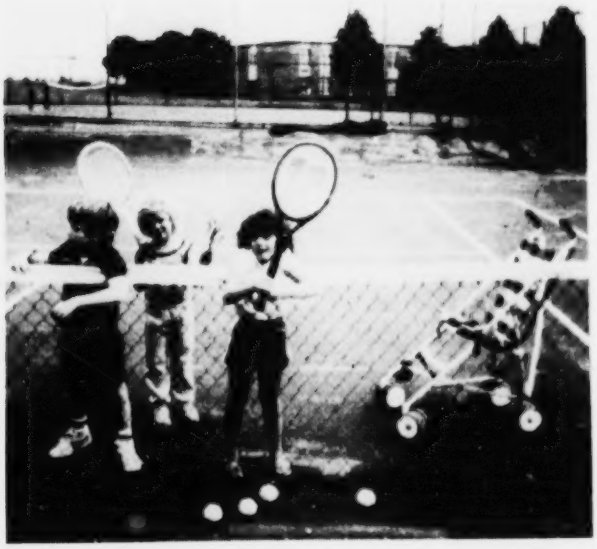
This was recognition time for us as a family, too. It was a time of redefining our image and sense of connection; a time of locating a system of people whom we could trust for consolation and advice, and a time for putting into place the network for support throughout Raymond's entire life. Raymond's birth into our family had significantly affected the paths I had chosen, especially in becoming an active father in the lives of *all* my children and in pursuing my Doctorate degree.



Maybe we should be thankful that he's alive--or should we?

That is a thought that I have had to systematically remove from my mind, in order to dry the tears and live in peace with myself.

Now, only in those moments when the kids are playing tennis or riding bikes, does my mind sometimes drift back to the thoughts of what might have been.

As I have grown more aware of Raymond's special needs, my own fatherhood and maturity have evolved. In some respects, *I live for two people. Because Raymond cannot speak, I must speak for him.*

The Family:

Fears,

Fantasies,

and Facts in

the Dynamics Process

The Family

New births call for adjustments in family dynamics.

Whenever a new child enters a family, concerned parents may wish to plan carefully to ensure the proper balance within the existing unit. Brothers and sisters need particular care within the changing family. Sibling rivalries are normal, healthy, and expected.

> *The impact of special children is different, and greater.*

As Raymond moved through infancy into childhood, the demands for involvement by the rest of the family became more intense. Of course, Janice and I aimed to give equal time and attention to *all* our children, including Mitra and Jackie, who were born in the two years after Raymond. But Raymond's needs made incredible demands upon our time and energies. This made our goals neither realistic nor possible.

Once, on a family trip to Martha's Vineyard, Raymond was sharing the front passenger seat with my wife. He had grown fast, and his long legs kept kicking the radio controls, interrupting the Madonna recording that the rest of us were trying to enjoy.

Even though we wanted to include Raymond in the vacation, his need for constant attention prevented us from attending to the needs of our other children.

Who knew how many seagulls we passed on that trip? Or how many times we missed interesting comments made by our brood?

All parents hope that their children will experience meaningful lives, learning from failure as well as from success. But severely retarded children will always need huge assistance. Because many layers of people will be involved throughout a handicapped individual's lifetime, the parent (or guardian) must be the primary advocate to ensure the quality and continuity of a network of care.

These profound differences affect special families and their relationships in many ways. For these families, like ours, a different kind of family planning is necessary.

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Fears

Siblings of retarded children experience different kinds of rivalries, obstacles, and jealousies.

A friend of ours, Carolyn Kuethe, was six years old when her retarded brother was born. She remembers the powerful atmosphere created by an event she did not understand:

> *There was a sudden but sustained confusion and disruption within the family.*

This confusion eventually undermined the entire family foundation. Abruptly, three months after her brother Mike was born, he was never mentioned by her parents. He was not seen at all by Carolyn or her sisters for nearly fifteen years.

That kind of confusion and panic followed our recognition of Raymond's retardation. Janice and I came to uneasy terms with it, but we weren't able to evaluate the effect it was having on our older child. Even though we tried to involve brother and sister as a family unit, the whole experience was so overwhelming for all of us that we lived in a constant state of false hope. At times, this defense mechanism seemed necessary just to get through to the next day.

Fantasies

The anxiety that every family experiences during pregnancies was heightened in our case, since the cause of our son's handicap had never been clearly identified. We worried terribly that our other children would be born with mental handicaps.

One year after Raymond's birth, Janice gave birth to our second daughter, Mitra. Daughter Jacqueline was born eleven months later. This is the way Rachel described our family turmoil:

One question that still remains unanswered is the reason for Raymond's severe mental retardation. "The answer isn't as important to my mother, father, or myself as it was fifteen years ago, even though the need to know still lingers."

It's important to note what first made my parents think that there was something abnormal about my brother.

Because he kept his eyes closed for the first three months of his life, my mother believed that Ray was blind.

When he finally opened his eyes, they were extremely pale blue in color, and they danced frantically, resembling a tightly held rubber band plucked in the middle.

One night, my parents and I laid in their bed with all the lights off, and my mother shined a flashlight above Ray's eyes. She moved the light across his face from left to right, but Ray's eyes didn't follow the light. She was convinced that Raymond couldn't see.

For his own peace of mind, my father decided to identify anoxia as the cause of Ray's brain damage.

I also think they believed that somewhere behind the handicap was a normal child who would awaken some day.

In spite of our new reality, we chose to move on in our lives, hoping that the cause was not genetic. As the family continued to grow, we reasoned that Raymond would experience a normal family environment.

So, through the years, each of our other children grew and moved on to older playmates. And Raymond played with the youngest sibling. We were hoping that he would "catch on," but he didn't.

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Facts

As parents and successive siblings deal with their broken dreams, they unveil their individual traits. As the child grows older, and the family moves through challenges, the natural attraction to the newborn can go through many gradual and subtle changes. However, sometimes the impact on the family is immediate and profound. Mary Rentfrow, a family friend, speaks of the shock for her family and her newborn son:

The rest of the family stayed behind in the car as I took Jimmy in for the short, routine examination. Without a word to me, the physician glanced at my baby. He felt Jimmy's body, hands, and feet.

I thought, "He's not the least friendly or pleasant. Maybe we can find a different doctor before long."

Then he turned to me.

"Your baby is a mongoloid," he said abruptly, and he started to leave the room.

Shocked, and not really comprehending, I said, "Please let me get my husband. --Explain to him."

Four months later, a definitive diagnosis confirmed our worst fears. Our new doctor said, not unkindly, "Yes, we are certain. There can be no mistake. Your son is a mongoloid."

Then, slowly, quietly, my husband handed our baby to me, and we left.

Even though my husband remained with the family for twenty-four years before leaving us, this moment was symbolic of his desertion.

Sometimes, family members spin off into isolated pain. Other times, an existing family of young parents and siblings may surround and cling to a retarded child. In both cases, the suggestion of institutional placement can sound harsh, uncaring, unfair, and unnecessary. Mary's daughter remembers:

Something was very clear to me. My brother had caused terrible trouble, and my brother had disappeared. If I caused trouble, the same thing could happen to me.

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Alienation and loss can come even before the baby is born:

Mother was horribly afflicted with toxemia. Her exhaustion, irritability, and grossly swollen legs terrified us three sisters. I wanted my mommy back. On some level, I knew I'd have to wait for the new baby before things would be all right again.

But I never did get her back. Far from being the joyful event we had anticipated, Jimmy's arrival escalated the tension, caused endless tears, and sent us into individual tailspins of alienation which we couldn't begin to understand.

Sometimes siblings bond quickly with the new baby. They may even consider their special sibling to be "normal," because they've known the newcomer only with the condition of limitations. Sisters and brothers may oppose placement of their special sibling outside the family. They may see a threat to the child's welfare and sense the interdependency of all the family members.

Alienation sometimes develops later. As the special child ages, family profile and capabilities shift. Parents grow older. Siblings move into other social groups and eventually leave home. Support groups offer sound alternatives for evolving family units, but changes can result in isolation--from other members of the family and from the very programs that are geared to help.

Sometimes family unity actually works to support a family in denial. One family member can seem to coerce a choice between loyalty to the special member and preservation of the original roles within the family unit. A family member may feel forced into the role of family outcast or private traitor. As Mary expressed it:

> *Although Jimmy was now no longer at home, he was always on my mind. My husband seemed determined to forget him. He instructed relatives and friends not to speak of him. Honoring his wishes, I never mentioned our son.*

Mary's daughter confirms the family denial:

> *We never spoke of my brother again--or visited him--until Daddy left the family.*
>
> *Even though my father was a minister, a professional counselor, he invoked the cobbler's therapy at home: Everybody had shoes except the shoemaker's children. We were never allowed, much less asked, to express our feelings.*

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Sometimes the trauma of siblings is experienced as a confused mixture of love and anger. These are the words of an adult, whose retarded brother died during childhood. Here she recalls that her family was driven by fierce dedication:

My mother's total existence was geared towards the care and welfare of my brother. He was severely mentally retarded, non-verbal, and blind. He required feeding at 8 in the morning, 12 noon, and 5 in the afternoon, exactly, and every day. If feedings were delayed, he would become very angry. Despite his handicap, he had the timing of a genius.

Not all of us have responded to Raymond in the same way. We've simply tried to handle our family changes as well as we could. In Rachel's words:

Strangely, I think my mother is still slightly in the denial stage. She wishes "it" would just go away. For her, Ray is trapped inside, waiting to be released. She doesn't think of Ray as a child, because she can't deal with the reality.

My dad explains that she is a logical person, and that Raymond doesn't make sense to her. Initially, her attitude angered me, but now it just leaves me depressed.

I was now the father of a retarded son. My only previous contact with a retarded person had been a woman who lived in the small country town of Fort Valley, Georgia.

She used to pass our house frequently, talking to herself. My sisters, brother, and I would run and hide out of harm's way with curious laughter and confusion. We didn't understand what we were witnessing, or why she acted the way she did, but we didn't ever dare to have contact with her.

In contrast, Janice and I worked to position Raymond so that our own children's friends were not afraid to visit. We didn't hide him from them, nor did they feel the need to hide from him. The pride with which our children explained Raymond's handicap seemed to bring a sense of comfort to their friends. Neighborhood children took turns trying to communicate with him in simple sign language until, as with all children and play, games like baseball became more important.

After meeting Raymond, a seven year-old neighbor commented to her mother:

> *I think I can work with him.*

Our family's emphasis on well-positioned explanations has created a compassion in the children's personalities. My daughter Jackie, who was seven then, described the world of her handicapped brother to her friends in a way that underscores the blessings of dignity and strength which she sees in the experience of her big brother:

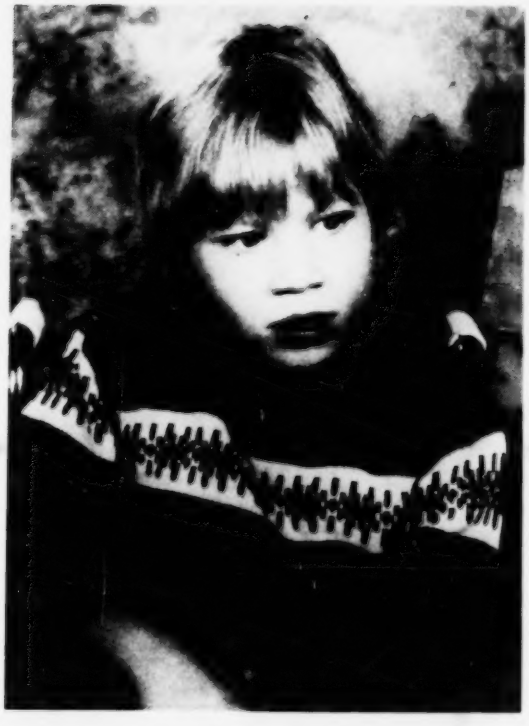
> *Raymond has changed my life because I understand different people. I get angry because he cannot explain to others how he feels when they stare at him for what seems like hours. But he is always happy and has a beautiful smile. I am proud to have a brother named Raymond III.*

That was one of the many times when Jackie's feelings toward Ray were positive. But there were other times when she became very upset with him because he had destroyed personal belongings in her room.

Our family unit made slow progress toward acceptance. We still needed to get definite answers to questions, not just for Raymond, but for the whole family. I wanted indications and projections, not just diagnosis. My wife, on the other hand, kept to her own sense of logic--as if Raymond were going to "snap out of it." She said:

> *"Raymond will tell us one day."*

Ten years after his birth, Raymond's doctor prepared a letter for insurance purposes:



> *After a review of the records, the best description I have for his condition is psychomotor retardation with spastic quadriplegia, more commonly known as mental retardation with cerebral palsy.*
>
> *There is no record of cause. Early separation of the placenta is mentioned.*
>
> *If you want to pursue the question of cause, consult a neurologist.*

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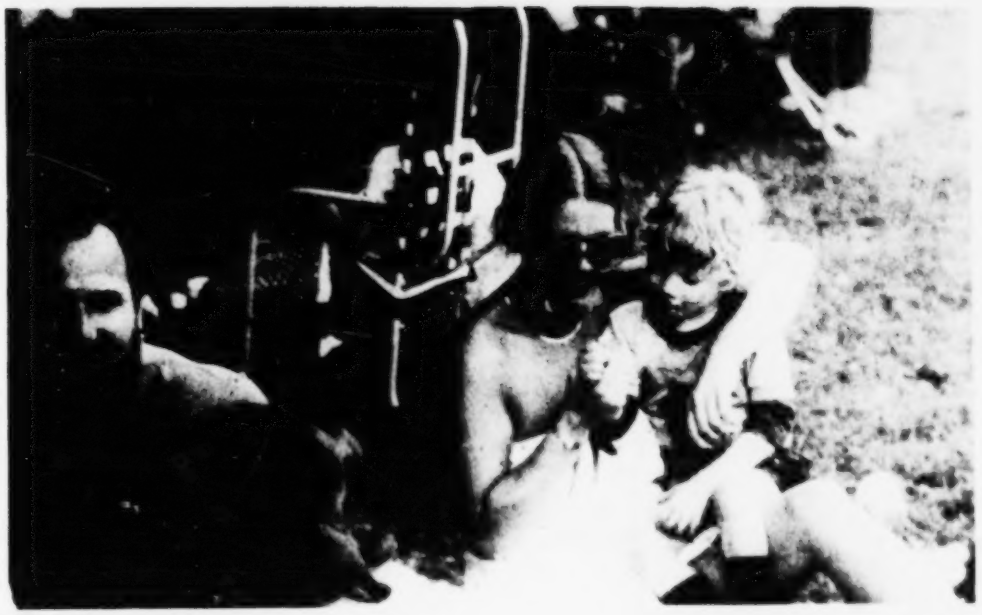
Eventually, we did get the information we sought. But the message finally came to us through our own observations, not through our son's words.



Reality Rollercoaster:

Schools,

Programs,

and Placement in

the Working Process

Reality Rollercoaster

My growing activism as the parent of a mentally handicapped child took me into public meetings. Other parents and professionals had information I needed to understand how best to keep our family balance while meeting Ray's needs. Soon I was giving talks and leading discussions about coping strategies for special families.

But at the very time that I was making presentations to help other families deal with their stressful situations, my *own* family was caught up in a web of stress. Too often, we felt as though we were riding a rollercoaster of never-ending family crises.

Even though Raymond was growing older, he continued to need the incessant monitoring which parents must provide for two-year-olds. Janice recalled:

I can remember returning from the pool one Saturday and leaving Ray in the recently-painted kitchen for a moment as I returned to the van to retrieve my wet swimsuit. When I got back to the kitchen, Ray's face was purple, and he was gasping for air. He had drunk a cup of turpentine left on the counter.

We tried to help him breathe.
We forced him to drink water.
We rushed him to an emergency medical facility
ten minutes away, and later
on to the local hospital.

I don't remember what the other children were doing while we took care of Raymond.

One fact loomed finally into focus: Raymond is different.

This incident illustrates the perpetual vigil that quietly divides parents from the other siblings who wait for their own deserved and needed attention. Our vigil also quietly divided Janice and me in our perceptions of the situation. I found out later that while I was driving Raymond to the emergency facility, Janice was also on her way there with the rest of the family. She had been painting and was frantic, thinking:

I made Raymond retarded,
and now I might have killed him.

As I rushed him to the hospital, I was wondering whether his death might be a better ending to the episode. But I couldn't admit my own thoughts until I found out that Raymond would be fine.

We didn't even consider placing Ray outside the family home until a friend convinced us that our family dynamics were suffering more than we realized.

In some respects, even talking about it--placing him in a home other than his own--seemed to undo all the painful work to keep him with the family. When Raymond was smaller and not so disruptive, home placement was easier to disregard as an option. But we couldn't ignore the signs any longer. He was beginning to eat the wood from the window sills. On several occasions, we awoke during the night to find him sitting on top of his specially-designed bureau drawers. Caring for Raymond required a 24-hour, sleepless lookout. As he grew larger and stronger, the family faced the notion of a cut-off moment. We were seeing the real nature of what we could expect in the future.

Only my mother could impress upon me how imposing Raymond looked in the grocery store as he walked with arms flailing to keep his balance. I began to notice that people carefully gave him safe distance to avoid encroachment.

Throughout the early years, our connection with the Centers for the Handicapped (CHI), had encouraged us to work with Raymond's specialness in a public setting. Despite the confusion and over-sensitivity, that understanding helped us cross into the next stage of working with an assisting network. On one occasion, I was present during a United Way Campaign tour of the CHI facility. In the group was one of my neighbors, who asked about my involvement. His sensitivity and positive impressions took me further along towards my commitment to activism on Raymond's behalf, and toward my acceptance of the impact of Raymond's disability in social terms.

We were starting to establish the personality of our family's approach to support systems, and the framework of state and local agencies. In later years, the IBM Corporation recognized me for my contributions to special education.

Schools

By October of 1984, with the birth of our twins Natalie and Robert, we had become a family of eight. Ordinary weekday mornings included lunches to pack, homework to finish, and lost shoes to find--not to mention a few areas of confusion leading to high-pitched voices in the form of "Hurry Ups."

At the very least, Ray had to be bathed, fed, and dressed in time to meet the bus, which would wait six minutes at the circle, some 50 yards away at the end of the street. That distance was part of Raymond's development program for walking in a defined direction. As the critical moment of 7:20 approached each morning, family tension usually mounted, and Ray would begin to cry. The rest of the family realized that the only way to make our system work smoothly was to remain calm. There really were several mornings of cheerful conversations with the bus driver, while Raymond completed his morning constitution.

Just as before-school became the family stress barometer, after-school became a progress focus for us all. When our children returned home from school, we somehow pieced together a report on how the day had gone and what activities had transpired.

> *The highlight of the day was watching Raymond walk from the bus to open arms after a day in school.*

Raymond usually sported a big smile in anticipation of cookies, while we immediately opened his backpack for the daily report. Because Raymond is non-verbal, this information became more important and more pertinent. However, from time to time, the reports were so abbreviated that we couldn't get a good feel for his progress. As we developed relationships with his teachers, uncensored information gave us more of a base for understaning how Ray was progressing.

From age five until thirteen, Raymond attended Longview School, a special school for the mentally disabled in Montgomery County. There, I was helped across my second bridge. When he first transferred there, I began to making regular visits. There was some initial resistance, but some of the teachers were eager to embrace a concept of flexibility in visitation. However, this empowerment of parents challenges the traditional approaches. Parents of special children are off-balance and often in denial. The education system is trying to adjust to the changing demands of more educated parents. I learned that the scrutiny from confused, angry parents often combined with the school's jealous protection to form a control factor which was different in each location.

Once, I asked to meet with Raymond's teacher and principal in response to a report. The principal was so blunt and clinical in speaking about Raymond's program that I afterwards asked the teacher whose side the principal was on.

She replied, "Raymond's."

Programs

The world of mental retardation is a world of crises and needs. It transcends race, creed, color, education, and money. Every special-child network will naturally engender its own issues. Our family has done plenty of wrestling with protocols, and the rules of procedure that affect Raymond's development.

Sometimes, in our effort to establish "rules" which would help Raymond, we broke the rules that keep a system operating smoothly. We learned much about dealing with requirements, rigidity, and red tape.

Our progress toward flexibility has not been easy. We often meet with resistance from service providers, primarily because existing operations are not necessarily aligned with the changing needs of our son. Fortunately, we have worked with some very talented group representatives. Unfortunately, many of their ideas were thwarted by rigidity in a larger system. For example, in November of 1992, we initiated a request for educational equipment to support Raymond's home schooling program while he recovered from a serious scoliosis operation. Processing the request took nine months and numerous phone conversations about financial responsibilities and other turf issues. The explanation?

> *"We have not received the paperwork."*

Recently, we were trying to get for Raymond the special shoes he needed after a back operation. We were warned about two issues: providers need to know how they will be compensated, and parents need to know the timing and requirements involved. The approval process for the shoes was estimated to take four to six weeks, and the delay caused damage to Ray's feet.

Getting timely responses to changing needs is an ongoing challenge. Family and child function on "real time," not "staff time." Providers take weekends off, but the child's program doesn't close down. Obviously, programs cannot depend solely on administrators; programs must meet the needs of the child. There are many hours when services are unavailable, so requests during non-working hours go unanswered. The mismatch of "real time" and "staff time" results in many frustrations. We've had to learn how to cope with remarks like this:

"There are hundreds of kids waiting like yours."

Inflexibility in system protocols has caused delays, frustrations--even damage, but *adherence* to the protocols of Raymond's individual program has resulted in progress.

One of Ray's first facilitators, and later foster parent, was Mary Uhler Thomas. She worked with him each day, designed his exercises, and basically operated as a member of the family. Mary educated our family about Raymond's potential by teaching us the importance of consistency. She insisted that the whole family use the established protocols with Raymond. "No cheating!" was her rule.

Once, she even demonstrated the technique to encourage Raymond in his ability to lift a spoonful of applesauce to his mouth.

Another time, I returned home to find that the baby-sitter for our daughters had resigned and said she would not return unless Mary was fired.

The reason? The babysitter had ventured forth to finger-feed Ray, violating Mary's rules and invading her territory.

Mary's reprimand of the baby-sitter served notice throughout the family.

Mary was right. The babysitter was replaced.

Another time, our niece Kathy was helping Raymond eat. Since his weighted spoon was missing, she gave him a big serving spoon. With it, scooping up his food was easier. This method was the beginning of a new system. But it was also a continuation of the old system, respecting Mary's guidelines. With her help, we were crossing the next bridge: realizing that Raymond *really could* develop life skills.

In 1983, Ray was continuing to grow and had graduated from his white-and-blue striped collapsible buggy to a large cushioned chair with wheels. I clearly remember the prolonged silence of the staff during one meeting. I had just requested that Raymond be assisted in walking one mile per day, as part of his individual education plan at the school. I had initiated a plan *and* I had suggested a change in the routine. Obviously, the staff rarely witnessed those behaviors in parents of special children.

During subsequent visits, I frequently heard Raymond crying as an aide took him through this daily routine. But, in my mind, the training was far better than being confined to the traditional wheelchair.

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Once, because of a repair, I was forced to rent a wheelchair for Raymond. As I approached our house, with the wheelchair in the trunk and preparing mentally to unfold it, one of the neighborhood children came over to the car and announced, "Little Ray is walking."

It was an event that involved the entire neighborhood, all the children taking turns in starting off Ray. He tilted forward, catching himself by putting one foot in front of the other.

Parents ordinarily expect their children to learn how to walk by the time they're two. But we had been told that Raymond would probably never walk. Janice recalls that little Raymond and Mary both looked like zombies as they practiced walking in front of the house. Neighbors quietly watched the slow progress from their kitchen windows. When we saw Raymond finally walk at age eight, we had witnessed a miracle.

Two years later, Raymond suffered a grand mal convulsion. Longview School called to tell me that he was at Shady Grove Hospital. During a checkup after his release, I met a man who changed the course of Raymond's life.

Dr. Arnold Gale suffered from spinal paralysis, and he greeted me from a wheelchair. Apparently, he had some paralysis in one hand, too. As I shook it, I wondered how he could handle my son of sixty pounds. Dr. Gale immediately erased my reservations with his gentle, positive, and insightful approach. He acknowledged our efforts to develop Raymond and suggested that I contact the Kennedy Institute's Department of Psychiatric Behavior, with which he was formerly associated.

The Kennedy Institute was a catalyst--both for Raymond's developmental program and for my own improved understanding of his needs *and* his capabilities. During the next five years, an extensive program evolved for Raymond as he himself evolved. He learned to feed himself, walk, respond, and return the love that awaited him at every turn. The stages were slow and tiresome, but *any* progress was very rewarding for all of us.

Continuing my activist role, I coordinated and educated the families of those with special-needs who were served by the Montgomery County Board of Education. I talked with them about approaching Raymond's program with a system. They could use our examples as models for reaching their own goals. Fortunately, my employer was sensitive to my needs and allowed the flexibility necessary for balancing this commitment with my job.

In our last conversation before Dr. Gale moved on to California, I had provided an update and said thank you for his direction and inspiration. His response?

> **"P***ass it on."*

Several years later, I returned to Children's Hospital for the annual checkup and sought Dr. Gale's whereabouts. With a painful expression, the secretary tried to guide our conversation in another direction. Evidently, the doctor's condition had worsened dramatically, but instead of dwelling on the negative, we remembered the positive. Dr. Gale is one of those shining rays of hope and encouragement that we needed so much as we move through this special life.

Raymond's development inspired us. We turned our attention to searching for those things that motivated him. Those encouragements could be transferred into learning situations for essential skills, such as speaking and using the toilet.

We now knew that Raymond enjoyed swimming, walking, food, and music. Combining our information about his ability with his excitement for music, we taught him to lift a music box and move it from point A to point B. He eventually learned to use this skill in a supervised work setting, moving library books from the in box to the return box, or refilling soda machines.

Ray enjoys a special relationship with foster dad, Gary Thomas

This kind of success showed us that special children can encourage ingenuity and creative problemsolving in other people, especially their families.

In family terms, we were determined to project a positive attitude and our loyalty to Raymond was fierce and genuine. But it was becoming more and more apparent to us that the demands of caring for him had negative effects on relationships at home. Other siblings in the family needed closer parenting.

In terms of relationships outside the family unit, even ordinary, informal invitations among our circle of friends involved extensive planning to accommodate respite care. And, in practical terms, Raymond had outgrown the current public school program. Both his size and rate of progress required the addition of a care provider.

We needed more resources to meet Raymond's needs. Reluctantly, we decided to look into residential placement. About the same time, confirmation of our private decision came from a public source.

During the five years of Raymond's program with the Montgomery County Board of Education, the Board had provided support in unmapped territory. Legislation to support mainstreaming for special students was increasing, and parents were becoming more knowledgeable and empowered. Annual reviews of the developmental program indicated sustained progress that justified increased support and funding from the Board.

One day, a thoughtful educator, who had observed my family of six children, suggested that it was time to seek residential placement for the sake of all of us. He pointed out that Raymond's care was absorbing so much energy that I wasn't seeing the drastic effects--on Ray's own relationships, on our friends, on all of the siblings, and on my wife.

> *"Your other children need their father, too."*

So, after much discussion, we began the process of re-evaluating Ray and preparing for residential placement.

Placement

We approached this in two phases. First, we talked within the family about the advantages and disadvantages. Then, after we called the State of Maryland about placement, the Jewish Social Services Agency contacted us. JSSA's primary objective was to help us help ourselves, providing family assistance through the liaison of a social worker. Support meetings and funding helped us understand placement procedures and stabilize our family balance. Although Rachel appeared to understand the situation, the younger siblings had known Raymond only with his handicap, so they considered his retardation "normal" --at least for him. We used much family discussion and many therapy sessions to express our feelings, to lay everything out on the table.

Next, with much soulsearching and agony, we chose a facility. Our reluctance was enormous. Simply put, we couldn't bear the thought of Raymond in the hands of strangers. The bottom line for us:

> *No one can take care of your own children like you can.*

Then, even when State funding was approved to place Raymond at the Hillhaven Learning Center in September, 1990, we delayed his entrance until November. We waited until we were psychologically and emotionally ready as a family.

We had been given latitude in selecting the home with which we felt most comfortable. Hillhaven was a lovely, ten-acre converted horse ranch, with eighteen special children. The staff was ready to provide the expertise that would support Raymond's developmental needs. Even though Hillhaven was over a two hour drive from our house, we decided that we could manage to bring Ray home for visits twice a month. Further into the future, we envisioned a group home program that might one day meet his needs as an adult. We felt sure that Raymond's success at Hillhaven would be directly related to the coordination between our family and the staff. Finally, we were confident that we were doing what was best for Raymond. As the deadline loomed, we joined hands and took Ray to his new home.

The comfortable setting and caring staff seemed to guarantee a smooth transition for Raymond. But we hadn't anticipated his sensitivity to his surroundings. Raymond's awareness, along with interruptions in continuity, resulted in some problems and required important changes.

For instance, our careful documentation in Raymond's progress profile inadvertently misled the teacher taking over his program. Mary's report to the counselor had included a progress chart which reflected the efforts of the whole family. Hillhaven needed to know more about how Raymond operated by himself, especially his self-initiating skills. This turned out to be a critical need in the matter of Raymond's nutrition.

Raymond refused to eat.

Within six weeks, he had lost twenty pounds--one fourth of his body weight.

I didn't think that Raymond was really refusing food. But he was more aware of his unfamiliar environment than we had predicted, and I imagine that the staff were as determined as Ray to establish themselves in the new situation. They misunderstood his apparent refusal to eat. By their interpretation of our records, the staff expected him to eat independently. They assumed that if he didn't initiate eating, he wasn't hungry. I suspected that when Raymond seemed to be turning down food, he was actually showing his inability to understand the task and responsibility presented to him. Because his refusal was at first interpreted as a discipline issue, he was not being consistently fed. Once again, I needed to speak for Raymond.

Our efforts during his home visits couldn't counter the dramatic weight loss. So I took action to smooth out the conflicts. I made a video recording to provide Hillhaven personnel with an idea of Raymond's capabilities and the techniques to which he would react favorably. The video showed what Raymond was accustomed to, so we began to make progress.

There were significant adjustments to make at home, too, but right away, I was optimistic. I became more involved in other relationships within the family. Raymond's needs had been consuming much time and resulting in huge preoccupation. The other children had been trying to integrate their needs with my availability whenever Raymond wasn't home.

Robert, our youngest, began to talk with me. The word "Dad" came more frequently in our conversations. Both Janice and I took up coaching for the youngsters' sports teams, joined scouting events more actively, and participated as school role models.

Soon, the pain of placing Raymond outside our home was mitigated by the increasingly apparent good for all of us. In losing Raymond part of the time, we seemed to gain the remainder of the family for the rest of the time. But the benefit was not without incidents that highlighted the costs. For instance, we were unprepared for the emotional burden of our first vacation after Raymond moved to Hillhaven.

Our original plans had called for picking Raymond up at Hillhaven, in Delaware, on our way to the traditional Thanksgiving dinner with Aunt Naomi in Philadelphia. We were especially excited about the occasion because we hadn't seen him since the move.

I knew that I would, as usual, be occupied with Raymond during his waking hours on the trip, carefully supervising his movements in new environments. Furthermore, the sleeping arrangements would require that I hold him in bed, because I knew he would not sleep in unfamiliar surroundings.

Just before leaving, Janice proposed that we pick Raymond up *after* Thanksgiving, on the return trip. Because her suggestion meant separating the family, I had reservations, but I agreed.

We thought of Ray often during the holiday, but the kids and I thoroughly enjoyed the parade without the problems of taking him along.

We remembered him in our prayers and left early to include him in the rest of the weekend.

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Another time, Raymond was scheduled to go with us to Martha's Vineyard, but we dropped him off at Hillhaven on the way there. I had originally objected to the revision in plans, but this change freed us all to do things more easily, enjoying our house guests and assorted activities. And Janice and I had much more interaction with Robert, Natalie, Mitra, and Jackie.

On this trip, the thought occurred to me that Janice and I must be careful. Our own relationship seemed to have become dependent upon our connections with the children. We wanted to stay connected with each other, not just as parents.

Getting There:

Looking Back,

Where We Stand,

and What We Must Do in

the Future Process

Looking Back

About the time that the twins were born, I volunteered to speak to the Longview School parents' group about special children and their families. My presentation targeted family crises and suggestions for coping. That evening marked the coming together in my mind of Raymond's handicap and the beginning of my own mental balance. Discussions with other groups had taken me to Jewish Social Services, the University of Maryland, Montgomery College, and many other audiences. This home-style therapeutic approach led, in turn, to the conclusion that I could package information and experiences about Raymond and work toward an academic degree that would help Raymond and all of our family.

On June 28, 1992, I graduated from the Ph. D. program of Walden University with a dissertation about successful factors in group homes. The following September, I presented strategies to the State of Maryland for implementing Senate Bill #588, the return of out-of-state, special-needs residents. From there, I have moved full-time into related consulting, lecturing, and advocacy projects.

The past two decades have seen significant pieces of legislation which specifically address the advancement of handicapped individuals. In 1975, Public Law 94-142 mandated that all children between the ages of five and twenty-one are entitled to education. Recent legislation continues to provide direction for equal access to society and services for this segment of the population.

Aunt Naomi and
grandmother Pitts

"...to the extent that funds are available, to provide for and encourage the development of a continuum of quality education, treatment, and residential services for the children of the state in the least restrictive setting most appropriate to their needs."

As Maryland moved toward family preservation projects, I began to look for a way to return Raymond to a community-based program where we would be closer to him and still able to maintain the same level of services.

With the help of the Developmental Disabilities Administration, I designed a community living arrangement for the Montgomery County Board of Education to consider as a pilot program. In this way, our family could bring Raymond back from out-of-state placement.

In accordance with the plan, Raymond has returned to Maryland to live in a foster home and attend a community-based education program. This is a family-driven plan, in which a foster parent or facilitator ensures the continuity of life-skill training. The family must stay involved in both program management and accountability until such time as Raymond "ages out" of the public education system and is placed in a local group home program.

The program models the use of State funding and the principle of least-restrictive-environment to make more productive lives possible for special children.

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Where We Stand

Numerous teachers, social workers, caregivers, and other interested people have participated in the chores of Raymond's educational programs. All of us have our own perspective of his development. Accountability and funding are basic issues. But one critical understanding must be at the heart of all our decisions:

> *In the final analysis, we are the only advocates for our children.*

Understandably, parents of handicapped children feel off-balance--even paranoid--because of the very nature of their burden. Misplaced blame, frustration, and anger all aggravate the obstacles that threaten their access to needed services and support. The enormous emotional struggles can cause their energy and resolve to burn out. Concerns about both the immediate and the long-term welfare of special children can seem insurmountable. And the complex administrative tasks and procedures can generate adversarial situations.

In their attempts to implement legislation, government agencies can seem like enemies of the very families they are required to help. This antagonism can escalate as parents fearfully face their child's transition into adult programs. Clear information and accessible resources can be very difficult to find. Too many parents are left alone to provide care for their special child for an entire lifetime.

Actual management of the lives of special children is shifting from government interventions to programs that families oversee. The success in Raymond's case depends on a high-functioning family, working with capable support personnel--all of them managing the program elements on a timely basis.

As the primary advocates for our children, we are the real originators of the individual education plans and the controllers of the developmental thrust.

Sometimes bureaucratic inertia threatens to undermine our progress. One day, I heard from an official of the Board of Education, in reference to a call from a local council person. A current facilitator had complained about the critical and unnecessary delays in the pilot program implementation. A chain reaction would have exposed and discredited some key people within the process. To function within the system, I chose to quash the commotion.

Now I have worked out a different set of rules. I must act *only* in Ray's best interest. That means I must resolve--not participate in--the conflicts. I have learned that the daily urgency of Raymond's care often requires suppressing family anger. The focus of the family must *always* be Raymond's immediate and long-range welfare.

Safeguarding a special child is an exhausting responsibility. Our friend, Mary Rentfrow, has been coordinating her son's care for nearly five decades. She has cooperated with dozens of teams, hundreds of caregivers, and numerous evolving programs, bureaucratic snarls, and conflicting regulations. Although he has made life-skill progress over the years, her 44-year-old son is still functionally a toddler. And Mary is now 82, still discharging the duties of a single parent for a completely dependent child. She is Jimmy's one continuing advocate, but she knows she can't do this job forever. She has one fervent prayer:

> *"Please, God, let my son die before I do."*

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What We Must Do

In the spring of 1993, a national health magazine published an article about Raymond. The headline read:

> ***"Montgomery County Handicapped Child Takes a Step Toward Normalization for Those Who Will Follow; Returns to the Community under Senate Bill #588 Pilot Program."***

Here is part of another article:

COMING HOME

Under the guidelines of relatively new legislation, Raymond Pitts, III, a fifteen-year-old, mentally handicapped boy, has been reunited with his community. Asphyxiation at birth left Raymond severely and profoundly retarded. He functions at the intelligence level of a two-year-old and requires assistance in performing essential life skills, such as physical hygiene and toileting. Raymond's family, therefore, became committed to his development of survival skills that would enable him to live as independently as possible for the rest of his life.

Until Raymond was thirteen, he lived with his family and attended Longview School in Montgomery County, Maryland, which offered an Intensity Level V curriculum. His individual education program (IEP) emphasized the development of critical life skills necessary to function as a member of his family. The implementation of his IEP was structured as an extension of a flexible pilot program designed to enhance the quality of his education.

Collaboration between Raymond's parents and the Montgomery County Board of Education provided the first steps toward normalization for Raymond. His program provides a successful model for delivering special education services to the handicapped in "least restrictive" environments. With the help of grants and through the efforts of his family and the local board of education, an innovative learning program was designed for Raymond. The program stressed continuity between the classroom and home environments. This helped to accelerate his emerging skills. With the help of The Kennedy Institute in Baltimore, and the Georgetown Hospital Child Development Center in Washington, D.C., like skill protocols and compliance standards were developed and implemented. This cooperative effort has become a prototype for the benefit of other students.

Even though this pilot program was successful, the increasing demands of the collaboration process on both family and education system led to out-of-state residential placement in 1990.

Then, in 1991, the United States Senate ratified Legislation #588. This law allows children with special needs, now living in out-of-state facilities, to return to Maryland. For Raymond, returning will involve a state-approved foster care/special education facility, and in keeping with Legislation #588, existing funding will continue to provide for necessary services as defined in Raymond's IEP. But most significantly, his return calls for the creation of a local living environment in which both community and family are meaningfully involved.

The intent of this landmark legislation is to implement a more cost effective approach to meeting the needs of an identified segment of the handicapped population in the State of Maryland. It provides for and encourages the development of a continuum of quality education, treatment and residential services for the children of Maryland, to the extent that funds are available. Many families remain unclear and apprehensive about the program advantages and implementation procedures. A clear document of understanding between parents and state is needed to ensure the success of the legislation.

In June of 1991, Dr. Raymond J. Pitts, Jr. (Raymond's father) submitted a proposal for a Community Living Pilot Program to the Montgomery County Board of Education and the Special Education division of the Maryland State Department of Education. The proposal marked the initial phase of the pilot program for community-based living. While addressing issues of age, coordination, and individual need, the proposal focuses specifically on emerging life skills that enable people like his son, Raymond, to live as independently as possible in the least restrictive environment. Particular care is given to meeting state guidelines to position clients for state-approved adult programs as they "age out" of the public school system. Case management would be assumed by the newly-formed Systems Reform Initiative committee. That body would be responsible for coordinating comprehensive "wrap around" services, including training and inter-agency communications, that will extend resources aimed towards increased normalization.

The pilot program will serve as a tool for assessing the ways through which state and local agencies can embrace Legislation #588 and Family Preservation, and thus more effectively meet the needs of other out-of-state individuals. The success of the program depends upon high-functioning families and the retention and development of qualified personnel. It promises cutting-edge approaches and has earned the support of the Montgomery County Department of Special Education, Jewish Social Services, and the Maryland State Department of Education.

The ultimate goal of the pilot program is to provide a community-supported living arrangement which ensures that Raymond is well provided for and that he will continue to function. To achieve this goal, Dr. Pitts has proposed a plan which is based on these strategies:

- *To work jointly with the Montgomery County Board of Education and the Systems Reform Initiative to coordinate a state-approved program that will best meet both immediate and long-range needs through Intensity VI-level, "wrap around" services.*
- *To implement a channel through which other out-of-state residents can successfully return to Maryland under Senate Legislation #588.*
- *To take advantage of community support for mainstreaming handicapped individuals, using the support of the natural community, the corporate community, and the family unit.*

With proper legislative support and funding, families and administrative institutions can become better prepared to meet the challenges and understand the advantages of including the handicapped population--both children and adults--in the community as a whole.

Dr. Pitts, parent of six, hopes that each of his children will experience a meaningful life, learning from failure as well as from success. Today each of his children requires kind, consistent parenting. Unlike his brother and sisters, Raymond will require such parenting and assistance to care for himself for the remainder of his life.

As they work through the pilot, the Pitts family and others will have to direct their energies toward "what is best for the child." If the handicapped child's welfare is the focus of every step, the journey will be a successful one for Raymond and all children like him, who return home to Maryland communities.

As the primary advocates for our children, we are the real originators of the individual education plans and the controllers of the developmental thrust.

Dr. Raymond J. Pitts, Jr.
and his brother
Dr. Nat Pitts

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Getting There

Two years ago, Raymond was the unintentional hero of our family's Disney World vacation. After extensive oral surgery--removal of seven teeth, including four impacted wisdom teeth--both operation and physical recovery were successful, but Raymond became very tentative and unsure of himself. My concern was to minimize the pain and fear which threatened to cause withdrawal or regression.

In an effort to bring Raymond back and restore his confidence, we planned a family spring break at Disney World. Because he had been physically inactive during his recuperation, we rented a wheelchair for Raymond. This time, it was far from being the obstacle or embarrassment we feared. Much to the surprise of the other children, the wheelchair actually served as a resting place for family belongings, as well as a passport to the front of lengthy waiting lines. We all came home happy and refreshed.

Having Raymond in our lives is a blessing to all of us.

Yes, his birth as a retarded infant was a nightmare that I pray will not happen to other people. But life with Raymond has helped my transition into manhood and my perception of the importance of life itself. I am a worthier person, now that I have developed a keen sense of appreciation for even small things in life that we usually take for granted. Reflecting on our family's experiences with Raymond, I derive strength from knowing that I am doing the best I can for him and for *all* my children.

Being the father of a special family, I have witnessed the phoenix of understanding and compassion rise from the ashes of my disappointment and confusion.

I am learning to rediscover some of my own innocence.

We're all glad that Raymond is with us.

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About the Authors

Raymond Pitts, Jr., is the father of six children, one of whom is a severely and profoundly mentally-disabled son. Currently, Dr. Pitts serves as a member of the State of Maryland Subcommittee for the implementation of Senate Bill #588. His studies of critical factors in programs for the mentally handicapped led to his development of a model for successful group homes. He recently retired from 20 years of marketing management experience with the IBM Corporation.

Using his own family's experiences, Dr. Pitts reflects here on the life-long impact of special children on their families. Now 17 years old, Raymond Pitts, III, was one of the first cases to return [in 1993] from out-of-state residential placement to a Montgomery County community-based program under the auspices of the Systems Reform Initiative.

Carolyn Marchitell is the sister of a man with Down's syndrome. She has been teaching for more than twenty-five years in public high school and private college. In her research, consulting, and advocacy projects, she designs collaborative communication and management strategies for institutional change.

Dr. Marchitell's brother, James Michael Kuethe, now lives in an adult group home program operated by Ohio Valley Residential Services, supported cooperatively by Hamilton County, the State of Ohio, and federal agencies. James Michael, who is 44 years old, travels to work by bus to earn spending money. Their 82-year-old mother still coordinates his care. Her family's experiences dramatically illustrate the lifetime of challenges which face the families of special children.

The authors continue to work as researchers and advocates, developing and managing support programs to enhance cooperation among families, agencies, and institutions to meet the needs of mentally disabled individuals. They are the authors of ***Project Return: A Parent's Guidebook***, in which they explain their suggestions to families responsible for critically dependent children. ***Project Return*** describes how to assure, coordinate, and individualize wrap-around care.

Through the authors' special blend of personal experience and professional expertise, *Rays of Hope* provides heartening reflections and valuable insights for any family whose plans must include lifetime care for a special child.

EXCERPTS AND COMMENTS

RAYS OF HOPE illustrates the different ways two families are providing for their child. Clearly there is hope. Families should realize that they are not alone.

RAYS OF HOPE tells the journey of one special family through a father's eyes. I hope it will help someone who follows by, "passing it on."

--- Page 3

"We admire the show of love and dedication by families of special children as they take care of a special child."

--- The Visaggio Family

"Taking care of a special child has been very hard for our family. We must continue to protect the rights of our children. This book is an excellent source of strength."

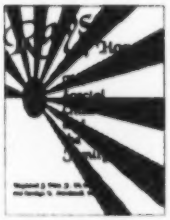
--- Parent

Being the father of a special family, I have witnessed the phoenix of understanding and compassion rise from the ashes of my disappointment and confusion.

--- Page 63

"Parent advocacy for your child is essential because it is through this process that both you and your child's teacher discover how your child learns best. When this information is known to both, an authentic partnership occurs and your child will progress."

Pat Lesnick, Ed. D.



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